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BRIEF REPORT **Open Access**

Experiences of acceptance among individuals with hereditary angioedema: a qualitative brief report

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Abstract

Purpose Hereditary Angioedema (HAE) is a rare genetic condition characterised by unpredictable swelling episodes that can affect almost any part of the body, with throat swellings posing a potentially life-threatening risk. Individuals with HAE commonly experience psychological difficulties, and unmanaged stress is known to increase the likelihood of attacks. As a result, psychological support may offer important benefits for this population. There is growing evidence that Acceptance and Commitment Therapy (ACT) can be an effective psychological intervention for people living with long-term health conditions. To consider the potential value of ACT-based interventions for HAE this brief report reviews data from a wider study exploring HAE life stories to examine how individuals with HAE experience acceptance.

Method Data were collected through open-ended qualitative survey responses from 65 individuals living with HAE. In addition, 11 of these participants also completed in-depth photo-elicitation interviews.

Results Many participants described how adopting an attitude of acceptance enabled them to engage more actively in life and supported their overall wellbeing. In contrast, some participants recounted times when struggling to accept their HAE led to heightened fear and anxiety, which they felt could trigger attacks and negatively affect their mental health.

Conclusions The participants' accounts illustrate examples of how accepting HAE diagnosis and its associated symptoms could support greater engagement in everyday life. These findings suggest that approaches aimed at fostering acceptance may offer a valuable means of enhancing psychological wellbeing in this population. The implications for developing acceptance-informed psychological interventions for individuals with HAE are discussed.

Keywords Hereditary Angioedema, Qualitative Research, Wellbeing, Psychology, Acceptance

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Introduction

Hereditary angioedema (HAE) is a rare inherited disease which occurs across all ethnic groups with prevalence of 1 in 50,000- 150,000 [21]. The pathological basis is a deficiency in the protein C1 inhibitor which has a role in immune as well as clotting pathways [6]. Individuals with HAE experience swellings which can affect almost any part of the body, although the usual sites include limbs, genitals, face, mouth and abdomen [18]. Attacks can be triggered by factors such as trauma, anxiety, or dental procedures, as well as routine activities like prolonged standing. Swellings involving the airway require urgent medical attention and can be fatal [20]. Recent advances in preventative and on-demand treatments have proved effective for reducing HAE attack frequency (e.g. [5, 19]). However, evidence for associated improvements in quality of life is mixed, with some studies reporting benefits [2, 29] and others finding no significant changes [23]. The condition therefore continues to have significant psychological burden for some patients [26].

Anxiety and depression are common co-morbidities of HAE with concern about the unpredictability of symptoms, slow routes to diagnosis and challenges to therapeutic management all potential contributors to psychological distress [26, 32]. Furthermore, as stress is perceived to be one of the most common triggers for HAE attacks [31], patients can become trapped in a cycle in which anxiety increases the likelihood of attacks, and the attacks themselves then further heighten anxiety [17]. Psychological interventions are therefore needed to support individuals living with HAE.

Evidence from other long-term conditions (LTCs) has illustrated that psychological adjustment is variable and can often occur irrespective of symptom severity or level of disability [9, 22]. In these cases, other psychological factors such as illness perceptions [11, 16] and coping approaches [15] can better explain variations in psychological outcomes. People living with LTCs in the United Kingdom can access psychological support for these factors through NHS Talking Therapies services, however outcomes are often poorer for individuals living with LTCs than for those without [27]. Traditionally, such interventions have been guided by cognitive behavioural theory which advocates that psychological distress can be reduced, and self-management enhanced, through the identification and modification of negative or unhelpful illness beliefs [1]. More recently, intervention models have proposed that some levels of distress are a natural and realistic consequence of LTCs and therefore do not need to be discounted or changed [12]. For example, acceptance and commitment therapies (ACT) focus on reducing the influence of any distress caused by LTCs through facilitating behavioural flexibility and the ability to undertake meaningful life activities and valued behaviours whilst becoming accepting of distress [10]. Though the evidence base for ACT is still developing, the approach has been applied in a range of LTCs [10] and is becoming increasingly adopted by healthcare providers [28].

This paper contributes to an understanding of life with HAE through presenting patient accounts in the form of qualitative data, which is well placed to develop understandings of the nuance and complexity of life with a LTC [3]. This report is part of a wider study that explored a range of HAE life-experiences. Themes relating to the experience of treatment and emergency care are reported elsewhere [32]. To consider the potential value of ACT-based interventions for HAE this brief report explores HAE life stories to examine how individuals with HAE experience acceptance.

Method

This study is reported using the Standards for Reporting Qualitative Research Criteria (SRQR) [24]. Further details regarding the recruitment, data collection and analysis strategy, are reported elsewhere [32].

Design

A qualitative research design was employed incorporating open-ended qualitative survey questions [4] and photo-elicitation interviews [33]. This hybrid design offered breadth, achieved through the higher response rates possible with the less time-demanding online qualitative survey, alongside depth and context-rich insight derived from the thick descriptions generated in the in-depth qualitative interviews [8].

Data were analysed using reflexive thematic analysis informed by a critical realist ontology, which posits that an external reality exists but that our understanding of it is necessarily mediated through interpretative processes [3]. Approval was gained from University of Staffordshire Health, Education, Policing and Sciences (Ref: SU20_190) ethics committee and the research has been conducted in line with the British Psychological Society code of Ethics and Conduct. All participants provided informed consent.

Sampling strategy

Adverts were shared by the charity HAE UK to their membership (approximately 650 members at the time of recruitment). Individuals who were over 18, living in the United Kingdom and with a self-reported confirmed diagnosis of HAE with C1 inhibitor deficiency were eligible to take part.

Data collection

Following consent, participants completed a qualitative survey on the platform Qualtrics. The survey included

Table 1 Participant characteristics

Characteristic	Survey Participants[a]	Interview Participants
Number; (% female)	42 (78%)	11 (55%)
Age: range, mean (SD)	19–79, 46.75 (16.57)	28–76, 53.09 (18.82)
Age of Symptom onset: mean (SD)	12.57 (8.9)	9.82 (6.32)
Age of diagnosis: mean (SD)	22.08 (14.93)	29.64 (19.93)
Hospital admissions in the last 12 months: mean (SD)	0–20, 0.73 (2.85)	0–1, 0.36 (0.50)
Average number of attacks per month in the last 12 months: range, mean (SD)	0–36, 3.62 (6.80)	0–13, 3.45 (4.45)
Prescribed prophylactic treatments[b]		
Berinert	9 (14%)	1 (9%)
Cinryze	6 (9%)	1 (9%)
Lanadelumab	5 (8%)	-
Danazol	10 (15%)	2 (18%)
Berotralstat	5 (8%)	2 (18%)
Tranexamic Acid	7 (11%)	1 (9%)
Icatibant	4 (6%)	-
Other	5 (8%)	-
None	14 (22%)	2 (18%)
Access to at home treatment		
Treatment available at home	55 (85%)	11 (100%)
No treatment at home, attends hospital for treatment	5 (8%)	-
Other	5 (8%)	-
On demand medications[c]		
None	2 (3%)	1 (9%)
Berinert	16 (25%)	6 (55%)
Ruconest	1 (2%)	-
Icatibant	27 (42%)	6 (55%)
Cinryze	5 (8%)	1 (9%)
Danazol	7 (11%)	1 (9%)
Tranexamic acid	6 (9%)	1 (9%)
Other	1 (2%)	-

[a] Statistics include data from participants who also took part in interviews

[b] Some participants had access to more than one medication type

[c] Treatments for acute attacks administered either at home or in medical settings, some participants had access to more than one medication type

open-ended questions about life experiences with HAE (see supplementary material for survey questions). Following the survey all respondents had the option to volunteer to be interviewed. Those who volunteered completed a second online consent form and were invited to send the research team up to five personal photographs of things they felt best represented their life experiences with HAE. This photo-elicitation process reduces the power-imbalanced created within traditional researcher-led interviews and facilitates participant-led discussion about issues of importance within their lived experience [33]. Participants were able to submit images of anything that they felt was important to help the researchers understand their experiences, they could opt for their photographs to be used only for the purposes of conducting the interview and analysis or could specify photographs with permission for inclusion in publications. Interviews were conducted online or via telephone to support nationwide recruitment. Interviews lasted up to two hours and involved discussion of the participants photographs; this discussion was further supplemented by broader focus on life stories using a semi-structured interview schedule (see supplementary material for interview schedule). Participants could choose to pause, reschedule or end participation at any point without being required to give a reason and were provided with a debrief sheet including contract details for support services. Interview recordings were transcribed with all identifying information removed and pseudonyms allocated for anonymity. As an incentive, survey participants were entered into a shopping voucher prize draw, and interview participants received shopping vouchers for participation. Data were collected between September 2021 and April 2022.

Participants

The qualitative open ended survey data were collected from 65 participants (42 female, 23 male) aged from 19 to 79, with a mean age of 46.75 (*SD* = 16.57). The mean age of onset of HAE symptoms was 12.57 (*SD* = 8.90), the mean age of diagnosis was 22.08 (*SD* = 14.93) and the average amount of time between the onset of HAE symptoms and receiving a diagnosis was 9.51 years (*SD* = 13.41). Eleven participants completed in-depth interviews, representing a medium-sized sample for both data collection methods [4]. Interview participant ages ranged from 28–76 years (mean 53), 6 were female and 5 were male. The mean age of HAE symptom onset was 10 years, and mean age of diagnosis was 30 years. Further participant characteristics including prescribed medication types are detailed in Table 1.

Data analysis

Qualitative survey responses and interview transcripts were analysed using reflexive thematic analysis [3]. Analysis began with the interview data which provided rich and thick descriptions of experience appropriate for in-depth qualitative exploration [8]. Interview transcripts were divided between AB, AO, DH and IL-W. The analyst team read and familiarised themselves with their allocated data and completed systematic coding before generating initial themes. As part of the analysis process the photographs were used to support researcher interpretation of the interview data though providing multi-modal insight into participants lived experiences [33].

The analysts met to discuss the developing themes and create a table capturing all themes identified across the interview data set. AB used this table to review all the transcripts and extracted data representing each theme. AB then reviewed these themes iteratively against the less rich data collated from the online qualitative surveys. Additional extracts from the qualitative survey data were extracted and added to the table for each theme, no new themes were represented in the qualitative survey data. AB produced a theme narrative which was reviewed, edited and agreed by all authors. This brief report focuses on the theme narrative regarding acceptance experiences.

Reflexivity and quality

AB, AO, DH, and JE were academics with no prior experience of working with individuals living with HAE. They contributed to study design, data collection, analysis and write up. IL-W was an MSc graduate and supported with data collection and analysis. LD is a consultant immunologist who regularly works with HAE patients and initiated the project due to a desire to better understand their patients. They contributed to the project design and supported with interpretation and application of the findings but were not involved in the analysis process.

All members of the research team involved in data collection and analysis engaged in reflexive practice. Group discussions took place during which the full team reflected on their subjectivity and role in the creation of the themes. To enhance the quality of reporting [30] findings are illustrated through a range of extracts from participants across the survey only and interview samples.

Results

In line with the aims of this brief report this results section presents findings relating to the participants stories of acceptance and the role acceptance played in their experience of living with HAE. The findings are presented as three themes: 1) Conscious acceptance: *"I won't let it stop me",* 2) The re-bound effect: *"The more I try to contain these feelings the more likely I am to end with an HAE attack",* 3) Accepting the down times: *"Life's there for living".*

Conscious acceptance: "I won't let it stop me"

Several participants described how coping with the unpredictability of HAE was often facilitated by taking the position of acceptance of the condition and an '*I won't let it stop me*' attitude. For some participants, this attitude could prevail despite long histories of negative experiences where '*life was put on hold*', particularly prior to diagnosis:

> *In the early days I can say, I can honestly say I think it's spoilt a lot of my life. I wouldn't say it's ruined it, it spoilt a lot of my life, it put my life on hold. How has it affected my life? It's affected my life in the way of… you can't just… how can I say? It's weird, you can't just up and go on the spur of the moment cause you've gotta think right, I need to take this, I need to take that, I need to make sure I've got my letter [about HAE diagnosis to show in an emergency situation], I need to make sure I've got this […] So in that way, I suppose it's hindered my life in many ways before being diagnosed, and even now it, it does affect your life. Doesn't stop it, I won't let it stop me doing what I wanna do and going where I want to go. (Maria, Interview)*

Many participants presented HAE as placing restrictions and boundaries on their lives, both before and after diagnosis, but also advocated that acceptance was essential for living well within these boundaries. This could be supported by self-talk:

> *You have to kinda say to yourself, right I know I've got this condition, these are the, these are the boundaries that it places on my life, so... I'll live within the boundaries, and I won't worry too much about what's going to happen the next day because... it can change its path, you know, one year to the next... it might one day it might catch me out, do you know what I mean? But if you worry about that forever, well you'll never do anything will you? So, you know, we're all gonna go one day, do you know what I mean?... I'm 57, I'm still here, so it's, yeah, I think that the main thing is just don't ignore it, because if you ignore it you won't do anything to manage it, so you have to be aware of it, you have to manage it, but you have to not focus on it, you know, all the time. Just get on with whatever you need to get on with, really. (Alan, Interview)*

For Alan this was a conscious acceptance, highlighting the difference between acceptance, where an individual acknowledges and continues to manage with their condition, and avoidance, where the adaptions required to live with the condition may be ignored.

The re-bound effect: "The more I try to contain these feelings the more likely I am to end with an HAE attack"

Some participants described a re-bound effect whereby engaging in avoidance and pushing thoughts away led to exacerbation of these thoughts and an associated impact on their mental health. This left them with an ever-present worry and fear about what might happen next:

> *Always in the back of my mind. I worry for my young son as to how his experience of HAE will be. There is always fear that I may have an attack which is very serious. But I try to block out those thoughts. (Simon, Survey)*

> *Tiredness. Pressure at work. Emotional stress. Frustration. Fear. Anxiety. The more I try to contain these feelings the more likely I am to end with an HAE attack (Erica, Survey)*

For some participants, the decision to avoid and contain the emotional impacts of the condition could then lead to an increased likelihood of attack. For others, the constant worry was described as exhausting. The heightened anxiety could lead to the decision to restrict and limit activities, not due to the need for boundary setting but instead due to a feeling of fear:

> *It limits me in terms of physical activities, and it makes me worried about what will happen tomorrow (will I be ok or not). (Alison, Survey)*
> *It's made me over think upcoming events in case of an attack. Also to worry about any sign of stomach pain in case it leads to an attack. (Jenny, Survey)*

For participants who presented themselves as less accepting and constantly worrying, these ups and downs were associated with anxiety and emotional distress:

> *[HAE has impacted on my life because] It contributes to my anxiety, even with treatment the worry is always there […] It will always have an impact on my life be it physically or emotionally (Gemma, Survey)*
> *It's a pain in the backside to live with and some days it can beat you down and keep you there it smacks your mental health down the drain. (Alastair, Survey)*

These examples reflect HAE as bearing a significant psychological burden. For these individuals HAE is not seen as something that can be accepted and lived with but instead as a condition which inevitably and unavoidably impacts upon mental health.

Accepting the down times: "Life's there for living"

In comparison, acceptance facilitated living in-the-moment and valuing the "*good weeks*" while at the same time being pragmatic and prepared for the *"down times"*:

> *I might have HAE, yes, it's a pain in the arse, however, life's there for living and you can't limit yourself, so to speak. You know, it's just about again, dealing with it and not letting it be in the forefront of your mind, all the time, you know. There are good weeks, good months you know, and good times. But with HAE you've gotta be prepared for the down times, and you know, yeah, that's it really. (Maria, Interview)*

Those who viewed challenging symptoms as time-limited presented a more positive outlook which appeared to prevent them becoming trapped in psychological distress resulting from the "down times". Acceptance also enabled some to look back on their life-experiences positively, acknowledging the "*nuisance*" posed by HAE but also expressing pride that HAE had not prevented them from doing what they wanted to in life:

> *It's just annoying and it's a nuisance but, from a very early age I learned to accept it's a nuisance. I mean crikey, you know, life's like that, isn't it? You know we've all got a bit of a cross to bear one way or another and, I've accepted I've got it, it's a hell of a nuisance, but I like to think it's never actually stopped me doing anything. (Owen, Interview)*

For Owen this acceptance was supported by the perspective that everyone experiences challenges, and that HAE was simply one of those challenges which it is not possible to avoid. For others, this perspective also helped with recognition of resilience when faced with challenging symptoms:

> *I remember going to work one time and my hands being so swollen, I, I couldn't write anything down, so I just answered the phone. I still went into work; I didn't let it stop me. It was only when the abdomen really, really flared up that it ever stopped me doing anything. The limb swellings never stopped me doing anything. Had to adapt, but it never stopped me. (Carolyn, Interview)*
> *[I sent that photo] to prove that although I have attacks, I still carry on with life and won't let it beat me, you know. And that's how I've felt with HAE, even since you know, I've got the diagnosis, I've still done things whether I've had the attacks or not, I've just carried on with life, it hasn't ever stopped me from doing things. It hasn't got me down, let's put it that way. (Kevin, Interview)*

These stories of resilience and strength in the "down times" illustrated how life could continue despite attacks. A stoic attitude enabled a feeling capability even when experiencing swellings. Others highlighted how, despite potentially struggling with acceptance early on, they found that once they were able to accept their HAE this eased the psychological burden:

> *I have had it since my early teen years, so it has impacted my life greatly, although I find it hard to say in what ways exactly. It has forced me to have a hard look at how able I was to perform well in the way society expects us to perform, and have strug-*

> *gled with the idea that I need to take a lot more time off work, for example, than most people. It has also helped me keep the focus on more positive things, and I derive a certain patience and sense of purpose from HAE, that is maybe even higher than for my 'normal' peers. HAE requires a lot of patience and acceptance, but if you find it in you to accept the reality, then things get much easier, despite the evident physical limitations of the condition. (Callum, Survey)*

Callum's example illustrates the potential to move from a position of challenge and resentment towards one which accepts HAE as a life-long condition. For Callum this transition to acceptance improved his life and made living with HAE easier.

Discussion

This brief report illustrates ways that acceptance was perceived by individuals with HAE to influence their life experiences. For some, acceptance of HAE seemed to facilitate a realistic view of the boundaries the condition could require as well as an ability to review life experiences with a perspective of achievement and recognition of resilience. In comparison, others who appeared to struggle with acceptance described themselves as living in a constant psychological battle against the fear about when the next attack might occur. Some participants described this fear as causing understandable anxiety which could trigger further attacks and act as a threat to psychological wellbeing. The accounts also illustrate examples of how some individuals move from a position of distress and avoidance towards one of acceptance and that this can have psychological benefits.

Acceptance is an emotion regulation strategy which does not seek to change emotions but instead lets emotions occur without feeling the need to control or minimise them [12]. For those with HAE, acceptance can be related to an acknowledgement that attacks will happen, and that they will likely experience 'bad days' but that these moments are temporary. In comparison, living in constant fear and worry about when an attack will happen was described by some as living in a constant heightened state of arousal and stress which is a known trigger for further HAE attacks [26] and is an ever-present psychological burden. Illness or symptom acceptance is known to be a psychologically protective factor in other health conditions including rheumatoid arthritis [7], multiple sclerosis [13] and HIV/AIDS [25] and these accounts illustrate how supporting acceptance may benefit patients with HAE.

It is important to note that the sample was limited by recruiting volunteers from a charity support organisation whose experiences may differ to those not accessing charity services. These individuals may report more positive experiences due to the additional support accessed, however there was evidence of poorer adjustment in the accounts of several participants which suggests that some individuals with HAE might benefit from interventions employing techniques that facilitate acceptance and psychological flexibility. Further research should also explore how other contextual factors, such as experiences of on-demand and long-term prophylactic medication use, may interact with psychological processes such as acceptance.

Conclusion

These findings highlight examples of individuals who reported approaching their HAE with acceptance. These participants provided descriptions of the positive coping experiences and indications that they chose not to limit their activities due to fear of attacks. This perspective could have meaningful implications for wellbeing and overall quality of life. While there are limited randomized controlled trials on the use of Acceptance and Commitment Therapy (ACT), early evaluations suggest this approach shows promise for helping individuals to live with and manage long-term conditions [10]. Self-guided online ACT interventions have been shown to be effective for improving mental health [14] and these methods might be particularly well suited as a quick to implement and resource-light approach for rare diseases like HAE. More research is needed to assess the impact of acceptance-based coping on psychological outcomes for HAE, and ACT informed interventions should be trialled and evaluated for this population.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1007/s44162-026-00192-4.

Supplementary Material 1.

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Authors' contributions

CRediT author statement: Burton: conceptualization, methodology, formal analysis, investigation, data curation, writing-original draft, writing – review and editing, visualization, supervision, project administration, funding acquisition; Owen: formal analysis, investigation, data curation, writing – review and editing; Herron: formal analysis, investigation, data curation, writing – review and editing; Elliott: formal analysis, investigation, data curation, writing – review and editing; Lindsay-Wiles: formal analysis, investigation, data curation, writing- review and editing, project administration; Diwakar: conceptualization, methodology, writing-original draft, writing- review and editing.

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Data availability

Data is available from the authors on request to the corresponding author.

Declarations

Ethics approval and consent to participate
The Health, Education, Policing and Sciences Ethics Review Committee at Staffordshire University approved our survey and interviews (approval: SU20_190) in July, 2021. The research has been conducted in accordance with the British Psychological Society Code of Ethics and Conduct.
Respondents gave written consent before starting the survey and/or written and verbal consent before starting interviews.

Consent for publication
Participants provided written informed consent for the research to be published in an academic journal.

Competing interests
Conflict of Interest: AB has received honorarium payments and hospitality costs from CSL Behring and Takeda for delivery of activities relating to HAE. The author(s) declare no additional potential conflicts of interest with respect to the research, authorship, and/or publication of this article. Funding Statement: This work was supported by a grant from HAE UK (https://www.haeuk.org/).

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References

1. Beck AT. Cognitive therapy and the emotional disorders. New York: International Universities Press; 1979.
2. Bork K, Anderson JT, Caballero T, Craig T, Johnston DT, Li HH, et al. Assessment and management of disease burden and quality of life in patients with hereditary angioedema: a consensus report. Allergy Asthma Clin Immunol. 2021;17:1–4.
3. Braun V, Clarke V. Thematic analysis: A practical guide. London: SAGE; 2022.
4. Braun V, Clarke V. Successful qualitative research: A practical guide for beginners. London: Sage; 2013.
5. Christiansen SC, Bygum A, Banerji A, Busse P, Li H, Lumry W, et al. Before and after: the impact of available on-demand treatment for HAE. Allergy Asthma Proc. 2015;36:145–50.
6. Busse PJ, Christiansen SC. Hereditary angioedema. N Engl J Med. 2020;382:1136–48.
7. Gouveia JAP, Costa J, Maroco J. The first 2 years of rheumatoid arthritis: the influence of acceptance on pain, physical limitation and depression. J Health Psychol. 2015;20:102–12.
8. Geertz C. Thick description: Toward an interpretive theory of culture. In: The interpretation of cultures: Selected essays. New York: Basic Books; 1973.
9. Graham CD, Rose MR, Hankins M, Chalder T, Weinman J. Separating emotions from consequences in muscle disease: comparing beneficial and unhelpful illness schemata to inform intervention development. J Psychosom Res. 2013;74:320–6.
10. Graham CD, Gouick J, Krahé C, Gillanders D. A systematic review of the use of acceptance and commitment therapy (ACT) in chronic disease and long-term conditions. Clin Psychol Rev. 2016;46:46–58.
11. Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. Psychol Health. 2003;18:141–84.
12. Hayes SC, Luoma JB, Bond FW, Masuda A, Lillis J. Acceptance and Commitment Therapy: model, processes and outcomes. Behav Res Ther. 2006;44:1–25.
13. Kiropoulos L, Ward N, Rozenblat V. Self-concept, illness acceptance and depressive and anxiety symptoms in people with multiple sclerosis. J Health Psychol. 2021;26:1197–206.
14. Klimczak KS, San Miguel GG, Mukasa MN, Twohig MP, Levin ME. A systematic review and meta-analysis of self-guided online Acceptance and Commitment Therapy as a transdiagnostic self-help intervention. Cogn Behav Ther. 2023;52(3):269–94. https://doi.org/10.1080/16506073.2023.2178498.
15. Lazarus RS, Folkman S. Stress, appraisal, and coping. New York: Springer Publishing Company; 1984.
16. Leventhal H, Phillips LA, Burns E. The common-sense model of self-regulation (CSM): a dynamic framework for understanding illness self-management. J Behav Med. 2016;39:935–46.
17. Longhurst HJ, Bygum A. The humanistic, societal, and pharmaco-economic burden of angioedema. Clin Rev Allergy Immunol. 2016;51:230–9.
18. Longhurst HJ, Farkas H, Craig T, Aygören-Pürsün E, Bethune C, Bjorkander J, et al. HAE international home therapy consensus document. Allergy Asthma Clin Immunol. 2010;6:22.
19. Lumry WR, Craig T, Zuraw B, Longhurst H, Baker J, Li HH, et al. Health-related quality of life with subcutaneous C1-inhibitor for prevention of attacks of hereditary angioedema. J Allergy Clin Immunol Pract. 2018;6:1733–41.
20. Lumry WR, Castaldo AJ, Vernon MK, Blaustein MB, Wilson DA, Horn PT. The humanistic burden of hereditary angioedema: results from the Burden of Illness Study in Europe. Allergy Asthma Proc. 2010;35:47–53.
21. Lumry WR, Settipane RA. Hereditary angioedema: epidemiology and burden of disease. Allergy Asthma Proc. 2020;41(S1):S8-13.
22. Maillot F, Laueriere L, Hazouard E, Giraudeau B, Corcia P. Quality of life in ALS is maintained as physical function declines. Neurology. 2001;57:1939.
23. Nordenfelt P, Nilsson M, Lindfors A, Wahlgren CF, Björkander JF. Health-related quality of life in relation to disease activity in adults with hereditary angioedema in Sweden. Allergy Asthma Proc. 2017;38:447–55.
24. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89:1245–51.
25. Pérez JE, Chartier M, Koopman C, Vosvick M, Gore-Felton C, Spiegel D. Spiritual striving, acceptance coping, and depressive symptoms among adults living with HIV/AIDS. J Health Psychol. 2009;14:88–97.
26. Savarese L, Mormile I, Bova M, Petraroli A, Maiello A, Spadaro G, et al. Psychology and hereditary angioedema: a systematic review. Rhode Island: OceanSide Publications; 2021.
27. Seaton N, Moss-Morris R, Norton S, Hulme K, Hudson J. Mental health outcomes in patients with a long-term condition: analysis of an Improving Access to Psychological Therapies service. BJPsych Open. 2022;8:e101.
28. Thewes B, Brebach R, Dzidowska M, Rhodes P, Sharpe L, Butow P. Current approaches to managing fear of cancer recurrence: a descriptive survey of psychosocial and clinical health professionals. Psychooncology. 2014;23:390–6.
29. Wong JC, Chiang V, Lam DL, Lee E, Lam K, Au EY, et al. Long-term prophylaxis for hereditary angioedema: initial experiences with garadacimab and lanadelumab. J Allergy Clin Immunol Glob. 2023;2:100166–6.
30. Yardley L. Dilemmas in qualitative health research. Psychol Health. 2000;15:215–28.
31. Zotter Z, Csuka D, Szabó E, Czaller I, Nébenführer Z, Temesszentandrási G, et al. The influence of trigger factors on hereditary angioedema due to C1-inhibitor deficiency. Orphanet J Rare Dis. 2014;9:44.
32. Burton AE, Lindsay-Wiles I, Herron D, et al. Hereditary Angioedema patient experiences of medication use and emergency care. Int Emerg Nurs. 2023;71:101339. https://doi.org/10.1016/j.ienj.2023.101339.
33. Burton A, Hughes M, Dempsey RC. Quality of life research: a case for combining photo-elicitation with interpretative phenomenological analysis. Qual Res Psychol. 2017;14(4):375–93. https://doi.org/10.1080/14780887.2017.1322650.

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